



HEMOPHILIA FOUNDATION OF NEVADA

Jo Anne B. Barnheart, Commissioner
Social Security Administration
PO Box 17703
Baltimore, MD 21235-7703
Fax # :202-358-6079

January 26, 2002

Dear Commissioner Barnheart:

We are very concerned that SSA's proposed changes to the disability listings for bleeding disorders will categorically exclude the very individuals who, because of their persistent bleeding, are unable to perform work or, if minors, are unable to engage in age appropriate activities. We, therefore, are writing to express our concerns.

We are, respectively, the Executive Director and a member of the Board of Directors of the Hemophilia Foundation of Nevada ("HFNV"). The HFNV advocates on behalf of persons with bleeding disorders in the State of Nevada. Our activities include distribution of educational materials on bleeding disorders, coordination of hemophilia clinics in rural areas of Nevada, sponsorship of affected youth to hemophilia summer camp and guidance and advocacy with insurance company denials for care.

In addition to our work with the HFNV, we have knowledge and experience with the effects of bleeding disorders because we are members of the community. **Ms.** Paper has von Willebrand disease and is an Emergency Department Nurse. Ms Paper recently co-authored the world's first book on von Willebrand disease entitled "A Guide to Living With von Willebrand disease." Mr. Bayer has severe Hemophilia A.

We have reviewed the comments on proposed changes to listings submitted by three of the most respected national advocacy organizations for people with bleeding disorders: the National Hemophilia Foundation ("NHF") the Hemophilia Federation of America ("HFA") and Gentiva's A.C.C.E.S.S. Program. Rather than submit a needless repetition of their thorough and thoughtful observations, we simply express our complete agreement and urge the Agency to recognize that its proposed revised listings do not address the reality of the disabling nature and the appropriate medical treatment of hemophilia and other coagulation disorders.

Thank you for your consideration in this important matter.

Very truly yours,

A handwritten signature in black ink, reading "Renee Paper".

Renee Paper, R.N., CCRN
Executive Director

A handwritten signature in black ink, reading "Peter Bayer".

Peter Brandon Bayer,
Member, Board of Directors